The National Multiple Sclerosis Society is dedicated to ending the devastating effects of multiple sclerosis.

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The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience, and expert opinion, but do not represent individual therapeutic recommendations or prescription. For specific information and advice, consult your personal physician.

The Society publishes many other pamphlets and articles about various aspects of MS. To ask for these, or for other information, call the National MS Society at 1-800-FIGHT-MS (1-800-344-4867).

All our publications are on our Web site, along with handouts called “Basic Facts” on various topics. For a list, click the bar on our home page called “Library”. If you have no access to the Internet, just call your chapter and ask for a copy of the latest Publications List.

For additional information, some of our popular pamphlets include:

- MS and the Mind
- Exercise as a Part of Everyday Life
- Controlling Bladder Problems in MS
- Bowel Problems: The Basic Facts
- Fatigue: What You Should Know
- Stretching for People with MS
- Stretching with a Helper for People with MS

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Cover photo: A physical therapist works with a patient with MS in the Neuroscience and Restorative Care Center at the Mount Sinai Hospital. Photograph by Bill Stanton.

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Managing MS
Through Rehabilitation

by Lisa J. Bain
with Randall T. Schapiro, MD
The World Health Organization uses some terms you should know:

- **Impairment**—a problem in a body system or a body part that significantly deviates from the norm.
- **Activity limitation**—a problem in performing a task or action.
- **Participation restriction**—a problem in the manner or extent of a person’s ability to be involved in a life situation.

These terms are used by rehabilitation professionals worldwide to make distinctions important to problem solving.

Suppose your MS causes your left foot to drop down each time you take a step. This is an impairment called “foot drop.” It makes walking difficult and increases your chances of tripping. Trouble walking is an activity limitation. But foot drop can be corrected with a lightweight orthotic. For many people, using this type of adaptive equipment means living life as usual. But a fashion model would need to change or adapt her career because this impairment causes a participation restriction in the kind of work she does.

Rehab professionals will not try to fix every impairment. They will focus on reducing participation restrictions and activity limitations.
memory problems, sexual difficulties, bladder and bowel needs, and overall fitness.

**Restorative rehabilitation** aims to restore lost function. This usually involves strengthening and retraining muscles as well as adapting to decreased function with new techniques. Restorative rehabilitation is especially useful following an exacerbation or acute attack of MS symptoms.

**Maintenance or preventive rehabilitation** aims to preserve function even as the disease worsens. Preventive rehab may also help slow down losses of ability and prevent unnecessary problems or complications.

**Who Can Benefit?**

Everyone with MS, whether their symptoms are mild or severe, can benefit from rehabilitation! Recently published scientific studies have demonstrated sustained functional benefit for persons with MS who participated in supervised rehabilitation programs.

For those people with mild or “invisible” symptoms, a rehab approach stresses education, energy management, and physical fitness. Doing a rehab program early on can establish positive behavior patterns that will come in handy should other problems surface later. When disabilities are more severe, rehab focuses on making the most of existing strengths and abilities.

Rehab also has something to offer friends and family. Part of a rehab program may well involve learning how to deal with changes, modify environments to reduce restrictions, and teach other people how to give assistance in ways that are physically and emotionally beneficial to you.

A program can also help people protect their important personal relationships by helping individuals recognize the impact of their MS on other people. In other words, rehab may help you keep your perspective.

**Finding or Building a Program**

Your neurologist, family doctor, nurse, or other health-care professional may refer you to a rehab clinic or to therapists in private practice. Some therapies may be provided in your home through a visiting nurse agency.

Most comprehensive MS centers offer a team approach in which the medical, psychosocial,
and rehabilitation aspects of care are integrated. Integrated programs not solely devoted to MS can be found in physical medicine and rehabilitation (physiatry) departments of many major hospitals. They may be offered on an inpatient or outpatient basis and are usually run by a neurologist or physiatrist (an MD who specializes in physical medicine and rehabilitation).

Each person with MS has a unique set of symptoms and circumstances that requires a personalized combination of rehab techniques. Evaluation is the first step. In addition to assessing your physical abilities, cognition, and personal goals, your evaluation may also include an assessment of your environment to see if modifications to your home or workplace would be useful.

Whether or not you go to an MS center, it is important to be an educated consumer. You should consider the expertise and experience with MS of prospective therapists. The nearest chapter of the National MS Society is an excellent source of referrals.

A good source of information on assistive devices for people with disabilities is ABLE-DATA. (The National MS Society does not evaluate assistive devices, so we cannot

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### Things Your Doctor Should Know

In 2004, the Professional Resource Center at the National MS Society published an Expert Opinion Paper, *Rehabilitation: Recommendations for Persons with Multiple Sclerosis*. The paper was written for physicians and other health professionals. The main points of this paper are:

The Medical Advisory Board of the National MS Society recommends that people with MS be referred for assessment by rehabilitation professionals when there is an abrupt or gradual worsening in functional limitations or increase in impairment that has a significant impact on mobility, safety, independence and/or quality of life. It is also recommended that assessment for rehabilitation services be considered early in the disease when behavioral and lifestyle changes may be easier to implement. The frequency, intensity, and setting of the rehabilitative intervention must be based on individual needs. Third-party payers should cover appropriate and individualized services for people with MS.

This paper also includes an extensive bibliography with dozens of references to studies involving rehabilitation. Doctors may find this particularly helpful when there are insurance reimbursement issues.
Since walking requires balance, coordination, upper-body control, strength, and endurance, rehab for walking requires evaluation of all of these areas. MS symptoms that affect walking include weakness, tremor, visual disturbances, sensory changes, spasticity, or problems with balance and coordination. Physical therapy, medications, walking aids, and/or appropriate footwear may be needed. You may also need to adapt your home, workplace, or habits to maximize your mobility and safety.

Mobility aids keep people mobile, but accepting this concept can be difficult. Many people see aids as symbols of disability and as a sign of “giving in” to the disease. They are afraid that using an aid will lead to greater weakness, and so they refrain from using devices that actually enhance independence and prevent fatigue. It may help a bit to look on mobility devices as tools. A carpenter can’t work without proper tools,
and some people with MS can’t move about easily on their own without the proper tools. The tools for mobility are now lighter, easier to handle, more attractive, and more comfortable than ever. A PT can determine which mobility tools are appropriate to your needs and teach you the skills you need to use them well. The mobility “tool chest” includes:

- **Orthotics** (lightweight shoe inserts) to position a spastic foot properly or to brace the foot and compensate for **foot drop** (noticed when the toe of your shoe scrapes the ground while walking). This often leads to trips and falls. Wearing orthotics decreases fatigue and increases stability. **Ankle-foot orthoses or AFOs** to compensate for weakness of the legs. They decrease fatigue and help prevent injury from misuse or overuse of joints.

- **Canes** to provide support when balance and/or weakness of the legs are problems. If one leg is weak, the cane is used in the hand opposite the weak leg. Two canes can be used if both legs are weak.

- **Crutches** to give greater stability when weakness is more severe and canes cannot do the job. Forearm crutches, called Canadian or Lofstrand crutches, are especially stable and require less muscle strength than canes.

- **Walkers** to offer stability when the lower body is weak or balance is impaired. Wheeled walkers in bright colors with baskets, brakes, and pull-down seats are available.

- **Wheelchairs** or three-wheel scooters to provide mobility when walking, even with an aid, is fatiguing or impossible. These aids are often used by people who are able to walk but need to conserve their energy.

**Balance**
A PT can provide balance retraining through exercises that emphasize strengthening and flexibility. Balance can be improved through use of visual cues or techniques to reduce upper-extremity tremors. Relaxation training is often used as therapy.

**Weakness**
Weakness is addressed through specific exercises and various types of assistive devices.

**Spasticity**
Normal movements require a coordinated
sequence: As one muscle contracts, an opposing muscle must relax. MS can disrupt this process, resulting in the simultaneous contraction of opposing muscles. This is called spasticity. It may also be described as “increased tone.” The affected body part becomes stiff or unable to move smoothly and the person has sensations of tightness. Spastic sensations may range from neutral to mildly unpleasant to very painful. In severe cases, spasticity can even cause a limb to become “frozen” in a bent position, requiring immediate medical attention.

Spasticity can be managed with the help of a physician and a PT. A combination of medication, exercises, adaptive devices, and relaxation techniques may be prescribed. Exercise programs will likely include stretching and range-of-motion exercises. Exercise in a cool swimming pool is helpful because the buoyancy of the water makes smooth movements easier. Passive exercise (when someone else moves your body) is particularly effective for managing spasticity. Specific positioning can also help to decrease spasticity.

Physical fitness
Appropriately designed exercise programs are of enormous benefit to people with MS. Exercise helps maintain or even build endurance. After a flare-up of MS symptoms, exercise can help reenergize a person. A PT, physiatrist, or exercise physiologist can provide the best advice on a good program that includes aerobic and non-aerobic exercises. It is best to seek help from someone familiar with MS.

Pain from awkward positions
The medical term is “musculoskeletal dysfunction.” It results from unusual positioning of the body caused by MS symptoms. For example, hip, knee, or low back pain can stem from an odd standing position that a person has developed in an attempt to maintain balance. Fatigue can make this kind of pain even worse. Overuse of certain muscles to compensate for other muscles can also lead to pain.

A physician will need to determine whether your pain is caused by nerve damage or by musculoskeletal dysfunction. If the latter has occurred, a PT can devise a program of strengthening and stretching exercises, practice of proper positioning, and compensatory techniques, such as bracing or use of an assistive device, to prevent awkward or excessive use of joints or muscles.
The treatment of pressure sores becomes more difficult as the sore advances. It is imperative to see your physician if you suspect that a pressure sore has begun.

**Occupational Therapists (OTs)** focus on skills that require upper-body strength, coordination, and fine-motor control. These include all the “occupations” of daily life, such as bathing, toileting, household chores, and working at a job. OTs also focus on cognitive problems, and can assist with cognitive retraining and strategies to compensate for poor memory. Most important, OTs can help with energy conservation.

**Fatigue**
Fatigue is one of the most common symptoms of MS, and sometimes the most disabling one. It affects everything you do.

Your physician may prescribe medications and regular rest periods. Fatigue is also managed by conserving energy and working efficiently. OTs are the experts on labor-saving and energy-conservation techniques. Ask your physician for a referral if fatigue is disrupting your life.

**Pressure sores**
Many changes in the body may occur if mobility is severely impaired. A person who is immobile runs the risk of developing pressure sores, also called bed sores or decubitus ulcers. These occur when the skin breaks down from constant pressure, caused by sitting or lying in one position. This pressure cuts off the blood supply to the underlying skin, fat, and muscle. These ulcers usually occur over bony prominences such as the tailbone, buttock, heel, shoulder blade, elbow, and possibly the back of the head. Sores may also develop from friction to the skin. This is called shear and may result from sliding across a bed or wheelchair. The skin is much more likely to break down if it is moist or infected. Thus incontinence (not being able to control urine or bowel movements, or both) can add to the problem.

The best way to treat a pressure sore is to avoid developing one in the first place. Pressure sores can be prevented in the following ways: Get up or change positions frequently, or have someone assist you to change your position at least every two hours. Keep the skin clean and dry. And check skin for reddened areas or sores during self-care routines.
**Upper body function**
An OT can recommend exercises to improve the strength and coordination of your arms and hands. Doing so can improve independence and function in your daily activities.

**Driving**
Driving can be affected by many MS-related disabilities. An OT can assess your driving skills and determine whether the available adaptations will work for you. Testing should be conducted both in the OT’s office and on the road. Bear in mind that the laws regarding what kinds of testing and reporting are necessary vary from state to state.

Hand controls for braking and acceleration are available for people who cannot rely on their legs. Steering knobs can help people who have the use of only one arm. And wheelchair lifts can be installed in certain cars and vans for drivers and passengers who use scooters or wheelchairs.

**Computers and electronic equipment**
Computers open a world of recreation and job-related activities, but MS symptoms may require special adaptations. For example, people with vision problems can use computers with enlarged keyboards, magnifying displays, or text-to-speech programs that read aloud the material onscreen.

Electronic remote controls can be used for virtually all the appliances in an environment—lights, radios, telephones, televisions, air conditioners, even doors. An OT can help you determine which devices are most appropriate, and where you can get any training that’s needed.

**Daily occupations**
The “occupations” of occupational therapy include the everyday things you do—caring for yourself and your household, holding a job, recreation.

Bathing, toileting, dressing, eating, and household chores may become hard to do in the presence of certain impairments. An OT can advise you about techniques and adaptive devices to compensate for particular disabilities. The table on the next page illustrates some everyday activities.
### Everyday Activities

<table>
<thead>
<tr>
<th>Activity and Helpful devices</th>
<th>Helpful techniques</th>
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<tr>
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<td>Tub bench</td>
<td>Avoid hot water</td>
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<td>Hand-held shower</td>
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<td>Grab bars</td>
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<td><strong>Toileting</strong></td>
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<td>Bedside commode</td>
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<td>Armrests near toilet</td>
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<td><strong>Dressing</strong></td>
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<tr>
<td>Velcro closures</td>
<td>Sit while dressing</td>
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<tr>
<td>Button hook</td>
<td>Dress weaker side first</td>
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<tr>
<td><strong>Eating</strong></td>
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<tr>
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<td>Elbows on table for stabilization</td>
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<tr>
<td>Specialized utensils</td>
<td>Hold cup/glass with two hands</td>
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<tr>
<td>Wrist supports</td>
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<tr>
<td><strong>Cooking</strong></td>
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<tr>
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<tr>
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<td>Slide objects rather than lift them</td>
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<tr>
<td>Reachers</td>
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<tr>
<td>Electric appliances</td>
<td>Do heavier chores in the morning</td>
</tr>
</tbody>
</table>

Vocational Rehabilitation Specialists focus on retraining or use of adaptations and accommodations on the job. They may work independently or in consultation with your OT.

**Psychologists** help people learn ways to handle their emotional and cognitive problems and deal with the impact of MS on the family.

**Sexuality**

Neurologists, urologists, sex therapists, specialized nurses, and psychologists may all play a role in addressing sexual problems caused by MS. Men may have difficulty achieving or maintaining erections, or reaching orgasm; women may experience impaired sensation, numbness or tingling in the genital area, insufficient lubrication, or difficulty reaching orgasm.

MS also affects sexual responses indirectly. Fatigue, pain, bowel or bladder problems, and the emotional impact of having MS can dampen sexual desire.

Taking an active approach to sexual problems means that both partners explore adaptations in sexual expression. A psychologist can sometimes help start this process. Medical treatment to manage symptoms is part of the solu-
Speech/Language Therapists (or Speech/Language Pathologists) work with speech when MS makes talking difficult or causes swallowing problems. They can also help with problems in cognitive functioning, memory problems, and using language, which may stem from MS-related injury in the “thinking” part of the brain.

If it’s hard to speak or swallow
When MS affects parts of the brain that control muscles in the mouth, throat, or voice box, speech and/or swallowing difficulties may result.

To improve speech, the therapist may teach breath control techniques or how to speak more slowly with emphasis on key words. Voice amplifiers can help when a person cannot generate volume. If speech is severely impaired, other communication devices are available.

Swallowing problems may be helped by exercises, altering mealtime routines to promote relaxation, or by making changes in the diet, or the position of the body while eating.
If the words are wrong
Common language symptoms involve not being able to find the right word or using an inappropriate substitute word. These problems can be handled with compensatory techniques.

Urologists treat urinary infections, bladder problems, and sexual problems.

Bladder problems
Many people with MS experience bladder problems at one time or another. The most common problems are increased frequency or urgency, leakage, difficulty urinating despite having the urge to do so, and the inability to hold urine in the bladder. Sometimes the bladder does not empty completely, which can set the stage for urinary tract infections.

Diagnosis is the first step. Symptoms may then be managed by medications, diet changes, and in some cases self-catheterization, in which a small tube, or catheter, is inserted through the urethra into the bladder so urine can drain out. (This sounds difficult and painful, but most people can learn to do it easily and comfortably.) There are also exercises involving the pelvic floor muscles that may be appropriate.

Gastroenterologists focus on serious bowel difficulties.

Bowel problems
Constipation may occur because of MS-related neurological damage, or lack of exercise, inadequate fluids, or poor diet. The first line of therapy usually involves modifying the diet to include more fruits, vegetables, and whole grains, and six to eight glasses of water each day. If these measures don’t solve the problem, consult your physician or nurse. A gastroenterologist will be needed in difficult situations.

Incontinence, or loss of bowel control, is a much less frequent complication and may result from leakage around impacted stool. Stool bulkers, a regular “bowel program,” and medication may also be prescribed. A physiatrist may also be very helpful with both bowel and bladder problems.

Nurses—First and Last. A nurse can be the linchpin of your rehab program. If your physician is an MS specialist, the chances are so is your nurse. But even if this isn’t the case, nurses are trained to identify health problems, do assessments, and connect people to appropriate specialists. “Patient education” is on their job description and nurses will make
time to listen to your questions and teach you self-help techniques.

**A FINAL NOTE (ON COPING)**

Living well with MS means much more than getting treatment for symptoms, adopting new techniques, and adjusting to physical changes. It means accepting MS as part of your life. Accepting without giving in is not an easy task, and there is no one right way to do it.

Rehab provides some of the tools you need to take control of your MS rather than having MS take control of you. Counseling by a psychologist, social worker, or psychiatrist who has worked with people who have chronic diseases may be extremely helpful. Ask your doctor or your chapter of the National MS Society for a referral.

It may also be helpful to meet other people who live with MS. Support groups, self-help meetings, and trained peers with MS all provide a chance to share information and concerns. Ask your Society chapter about these programs. Asking for help shows strength—not weakness.